

Genetics Task Force Subcommittee Four Report

Subcommittee Title: The Use of Genetic Information for Other Social Purposes

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I. Background

II. The incidence of discriminatory actions based upon genetic information

A. Findings

1. The Task Force received little information on the incidence of discrimination based on genetic information in the State of Washington. Information provided by the Department of Health Genetic Services Section includes three cases in which family history or genetic status may have been used to adversely discriminate against an individual over the course of the last 10 years. The rest of the complaints were based on the need for additional education and/or resources.
2. The Washington State Human Rights Commission reported that no claims of discrimination based on genetic information have been received by the WSHRC.
3. Statistical tables used by life insurance companies inherently contain genetic information, as a variety of factors could be construed as 'genetic' and this is highly dependent on the definition of genetic information. For example, family history is a common and allowable question for insurance coverage but could potentially be included in a definition of genetic information.
4. Agencies do not systematically survey people or make proactive efforts to collect information regarding discrimination based on genetic information, but agencies such as DOH, OIC, and WSHRC have reporting systems in place for receiving complaints.
5. Health, life, and disability insurers view genetic information as a category of health care/medical information.
6. State laws and industry practice disallow the use of health information (including genetic information) to set rates for, cancel or non-renew a consumer of health insurance. Disability and life insurance may use health information to underwrite a policy but state law and/or industry practice prohibits the use of health information to cancel or non-renew a current consumer of these types of policies.
7. WSHRC interprets existing state and federal laws to be applicable in cases of employment or other discrimination based on genetic information, however this has not been challenged in the courts.
8. A minority of the subcommittee members is concerned that the protection provided by the Americans with Disabilities Act (ADA) against discrimination based on genetic information may be limited, particularly in light of recent Supreme Court rulings limiting the scope of protection provided by ADA.

B. Conclusions

1. Evidence of discrimination based on genetic information received by the task force does not suggest widespread problems regarding the use of genetic information for social purposes such as health, life, or disability insurance, or employment. However, the incidents reported to the DOH GSS may not represent all such events. Currently, quantitative data on the extent of actual or perceived discrimination based on genetic information may be lacking.
2. Existing regulatory policies and practices provide some protections against discrimination based on genetic information; in particular, state and federal laws protecting the privacy of health information and limiting the use of health information by employers and insurers provide important protections. However, one committee member believes that gaps exist in the protection provided by these existing laws. Examples of existing laws include the following:
 - a. The Washington Law Against Discrimination (RCW 49.60 et seq. and WAC 162-22 et seq.) prohibits discriminating against an individual based on genetic information in employment, real estate, public accommodation, credit, and insurance. RCW 49.44.010 also prohibits “blacklisting” by employers.
 - b. The Federal Americans with Disabilities Act has been interpreted by the EEOC as prohibiting discrimination based on genetics. See II.A.1. below.
 - c. Jon Hedegard of the OIC stated that, as applied to group and individual insurance, Washington State laws do not offer direct prohibition against the use of genetic information, but those laws are written in such a way that it is not possible. See, e.g., RCW 48.43 et seq.
 - d. RCW 48.18.480 prohibits unfair discrimination in insurance matters, and the OIC has heard of no problems in this area.
3. One subcommittee member recommends changing RCW 49.60, the Law Against Discrimination, to explicitly include “genetic information” in the list of characteristics that receive protection under the law. As it is written, the law only explicitly protects discrimination based on “sex, race, creed, color, national origin, marital status, age or the presence of any sensory, mental or physical disability, or the use of a trained dog guide or service animal by a disabled person. In addition, a minority recommend that the Uniform Health Information Act be amended to define genetic information obtained as a result of participation in human subjects research be defined as medical information. The remaining subcommittee members believe that no additional safeguards are needed in either area of the law.

C. Recommendations

1. The subcommittee did not identify any areas in which additional legislation was deemed necessary for the protection of individuals against discrimination based on the use of genetic information in insurance or employment settings.

III. Strategies to safeguard civil rights and privacy related to genetic information

A. Findings

1. Findings A minority of the subcommittee members believed that Washington State's consanguinity laws regarding marriage may be a violation of privacy rights and should be reviewed. RCW 26.04.020 lists conditions under which marriage is prohibited in this state. RCW 26.04.020(1)(b) specifically prohibits marriage "when the husband and wife are nearer of kin to each other than second cousins..." However, current data indicate that the genetic risk for progeny of first cousin marriages is only minimally increased above population risk. "Genetic counseling and screening of consanguineous couples and their offspring: recommendations of the National Society of Genetic Counselors." Journal of Genetic Counseling 11(2) April 2002, 97-119.
2. The ADA and EEOC rules define the type of information an employer can request and use in making employment decisions. The ADA states that before making an offer of employment, an employer may not ask job applicants about the existence, nature, or severity of a disability. Applicants may be asked about their ability to perform job functions. A job offer may be conditioned on the results of a medical examination, but only if the examination is required for all entering employees in the same job category. Medical examinations of existing employees must be job-related and consistent with business necessity. The Equal Employment Opportunities Commission (EEOC) writes rules pertaining to, and oversees the implementation of, the ADA. The EEOC rules address the retention, storage, and use of employee's health information. The EEOC interprets the scope of the ADA to include genetic tests and genetic information. The EEOC considers that employers who discriminate against employees on the basis of predictive genetic tests "regard" the employees as having a disabling impairment and are therefore acting in violation of the ADA (2EEOC Compliance Manual, secs. 902-45, March 14, 1995).
3. Both state and federal law protects the privacy of medical records. The following list provides examples of such laws:
 - a. The federal act, HIPAA, provides individuals in the large group health insurance market with new national privacy rights, which are broadly enough defined to include genetic information. There is a specific provision that precludes the use of genetic information for insurance purposes. Less restrictive state laws are preempted. HIPAA does not provide protection for the individual or small group health insurance market.
 - b. The Washington Uniform Health Care Act of 1991 (RCW 70.02 et seq.) covers identifiable health care information in any form and applies to health care providers and insurers. DNA was added to the definition of "health care information" by ESSB 5207, which was passed by the Legislature in March 2002.
 - c. The Washington Uniform Health Information Act is based on the model law from which the federal law, HIPAA, was promulgated and provides similar protections.
 - d. The Washington State Patients' Bill of Rights also provides privacy protections and is applicable to insurers and third party payors.
 - e. WAC 284-04 et seq. also provides protections similar to those in HIPAA.

- f. The Governor's Executive Order on Privacy 2000 addresses privacy concerns in regard to state government agencies and contractors.
- g. Case law may also arguably prohibit the divulgence of genetic information, at least in certain circumstances, based on a 1997 case against Group Health Cooperative for using an employee's mental health records in a training session for administrative employees.
- h. RCW 49.44.010 prohibits "blacklisting" by employers.
- i. Joan Mell, an attorney and legislative consultant who testified before the task force, stated that state law reflects consistent protection of privacy of body and bodily functions.

B. Conclusions

- 1. Existing laws and regulations are sufficient to protect the privacy of individuals in regard to genetic information that is included in the medical record or obtained as a part of health care.
- 2. Existing state and federal laws as well as industry practices/policies provide protection for an individual's privacy and civil liberties with respect to health, life, and disability insurance.
- 3. Existing laws provide protection against employment discrimination or other privacy/civil rights violations.
- 4. The Washington State law prohibiting marriage of first cousins may not be justified on a scientific basis.

C. Recommendations

- 1. The subcommittee did not identify any areas of law in which additional legislation is needed to protect the privacy of individuals with regard to the use/disclosure of genetic information.
- 2. A minority of the subcommittee members recommended revising the Uniform Health Information Act to ensure that genetic information obtained in the course of research participation is included in the definition of medical information.
- 3. One subcommittee member recommended changing RCW 49.60, the Law Against Discrimination, to explicitly include "genetic information" in the list of characteristics that receive protection under this law.
- 4. A minority of the subcommittee recommended that repeal of the Washington State law prohibiting marriage of first cousins should be considered.

IV. Remedies to compensate individuals for inappropriate use of genetic information

A. Findings

- 1. Federal and state laws provide for civil and/or criminal penalties for violations of privacy and/or anti-discrimination laws.

B. Conclusions

- 1. The existing tort system contains an avenue to compensate individuals for inappropriate use of genetic information.

C. Recommendations

- 1. The Task Force did not identify any additional action required by the State.

V. Incentives for further research and development on the use of DNA to promote public health, safety and welfare

A. Findings

1. Biotechnology and research endeavors in Washington are sensitive to changes in legislation that may affect their ability to conduct research.
2. The Task Force heard from several presenters that fear of discrimination is a reason that people do not participate in genetic studies.
3. Research involving human subjects may be subject to different oversight requirements depending on the source of funding/regulation or level of anonymity involved in the data collection process.

B. Conclusions

1. Washington law must be such that biotechnology companies and other researchers want to locate or continue to remain and operate within the state.
2. Policies are needed to address the perception of the risk of discrimination associated with participating in a genetic research study.

C. Recommendations

1. The State implement programs or other processes to educate the public, researchers, employers, and health care providers about existing measures to protect an individual's civil liberties and right to privacy. Such a program may reduce the perception that the risk of discrimination is high and encourage people to participate in genetic research.
2. Any process to create policies to address the use of genetic information in research should invite participation from all stakeholders.